Healthcare-seeking strategies among displaced children in war-ridden northern Uganda: the case of malaria

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Received 10 March 2010, Revised 7 June 2010, Accepted 10 June 2010

A field study was performed to examine suffering and treatment seeking from the perspective of children aged 8–16 years living in war-affected northern Uganda. Various techniques for collecting qualitative and quantitative data were used, including a semi-structured questionnaire about illness experiences and medicine use over a 1-month recall period. The 165 children who were interviewed were attending primary schools for displaced children and/or commuters' night shelters.

The children frequently attributed their common febrile ailments to malaria and used a variety of pharmaceuticals and herbal remedies, as self-medication, for their self-diagnosed malarial episodes. Misdiagnosis of febrile illnesses by the children (as well as by the local healthcare providers) and frequent misuse of medicines in the treatment of these illnesses appeared to be very common.

Improvement of the health conditions of these children requires a change of focus. Firstly, children above the age of 5 years who are not under adult care and who are often no longer welcome in the local hospital's paediatric ward need to be accepted at the outpatient clinics currently intended for adults. Secondly, the local diagnostic system needs to be improved, not only so that malaria can be reliably diagnosed but also so that alternative diagnoses can be confirmed or rejected, otherwise the current over-consumption of antimalarial drugs may simply be replaced with an over-consumption of antibiotics.

The most recent armed conflict in northern Uganda lasted from 1986 to 2007. During this 'civil war', up to 2 million people were displaced (www.un.org/apps/news/story.asp?NewsID=12297&Cr=uganda&Cr1). To protect people from the wartime dangers, about 800,000 people in this region, mostly women and children, were moved to so-called internally-displaced-person (IDP) camps and 'protected villages'. Even these 'protected' communities suffered, however, from child abductions, epidemics of infectious disease and abject poverty. Although epidemiological data on the age-related morbidity and mortality that occurred in these communities are lacking, a report by the international aid organization *Médecins sans Frontières* (MSF) indicated that the children were especially vulnerable to malaria, diarrhoea-related illnesses, acute respiratory illnesses and anaemia (www.msf.or.jp/news/baseline/Baseline.pdf).

The health services in wartime northern Uganda were mainly provided by the national Ministry of Health, the main focus

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DOI: 10.1179/136485910X12743554760342

of which has always been the healthcare needs of children aged <5 years. Older children are rarely allowed consultations in paediatric units and, therefore, when ill, they must try to access the system for adult healthcare, where their vulnerability to infectious diseases and other forms of suffering is, in general, not sufficiently recognised. Children who are not under adult care, such as those in child-headed households, are at particular risk of being seriously neglected in terms of their healthcare. At the time of the last civil war in northern Uganda, many such children either lived permanently in the IDP camps and protected villages or travelled back and forth between such settlements and the Gulu municipality. These children were regularly exposed to the easily preventable and curable diseases associated with the dire circumstances in which they were living, while having little if any access to effective healthcare.

The present study forms part of a larger ethnographic investigation designed to examine the suffering and quest for therapy of the children caught up in the civil war in northern Uganda, from the perspective of the children themselves (Akello, 2010). Northern Uganda is considered to be a holo-endemic region for human malaria. The main aim of the present study was to determine what the children aged 8–16 years regarded as 'malaria' and what they did, if anything, to resolve the problem of 'malaria'.

SUBJECTS AND METHODS

Study Area

The fieldwork location was primarily Gulu municipality and the IDP camps that lay in the 'safe zone' formed from the land that lies within 7 km of Gulu. The two main fieldwork periods ran from July 2004–January 2005 and from July 2005–December 2005 but various short follow-up visits were made in 2006 and 2007. The first language of the children who were investigated, and the second language of the main researcher (G.A.), is Acholi.

Study Population

Over 500 children participated in the study. Each child investigated was aged 8–16 years and met at least one of the following three criteria: lived in child-headed household; attended a primary school for displaced children; and was the caregiver for an HIV/AIDS patient who was either registered in the Presidents' Emergency Plan for AIDS Relief (PEPFAR), at Lacor Hospital, or was a client of World Vision's Antiretroviral Programme. Owing to the high mobility of the children, few were covered by all of the various techniques of data collection employed in the study.

Data Collection

The field study combined qualitative and quantitative techniques for data collection. The children were requested to write compositions, narrate their experiences, discuss, list and rank the illnesses that commonly affected them, and to illustrate, diagrammatically, their past illnesses and what medicines they had used in attempts to get better. In addition, one researcher (G.A.) observed displaced children at primary schools, children's homes, nurses' clinics in commuters' night shelters, the drug shops where children bought medicines, and the places where children attended religious services for the sick. Children were also observed, over a 1-month period, at four state-aided healthcare centres: Gulu Regional Referral Hospital (GRRH), and the Laroo, Laliya and Layibi Health Centres. The hospital diagnoses that appeared in children's registers in the local hospitals' outpatients units and children's homes were also explored. Interviews about the diagnoses indicated in these registers were subsequently conducted with the relevant, local healthcare providers. Occasionally, professional healthcare providers were interviewed about the frequent diagnoses of malaria based only on complaints

of persistent headache (*abaa wic*), high body temperature (*lyeto*) and coldness (*koyo*). Accurate estimates of the true prevalence and incidence of malaria in the study area could not be made because a lack of facilities prevented any laboratory-based confirmation of a suspected case of the disease. In this text, the use of quotation marks around the word malaria indicates that the disease being discussed is the children's self-diagnosed ailment, and not necessarily true malaria.

In order to obtain statistical data, 165 children who attended primary schools for displaced children and commuters' night shelters were interviewed. In each interview, a semi-structured questionnaire was used to collect information about the interviewee's illness experiences and medicine use over the previous month. Twenty-four children were followed over a 6-month period and participated in several in-depth interviews and focus-group discussions.

Ethical Considerations

The study protocol was approved by the Uganda National Council for Science and Technology. The resident district commissioner, chief administrative officer and director of health services for Gulu district, the head teachers of the schools attended by some of the children investigated, and the non-governmental organizations that provided services to displaced children in Gulu district granted additional permission to conduct the research. All children who participated in this study gave their verbal informed consent. The children who reported the most harrowing wartime experiences were referred to the regional psychiatrist, for review and counselling.

RESULTS

The following narratives, of two of the children's experiences with 'malaria', indicate the typical symptoms reported by the study children and the medications that the children commonly sought to treat those symptoms.

This is how Ojok, a 14-year-old boy, wrote about his experience with 'malaria':

> *I used to go and do* leja leja [casual farm labour for money] *quite far from home during school holidays. One day I was coming back from Lacor village to Kirombe where I had gone to farm. It rained on me. By the time I reached home, I had headache and was feeling very cold. I lit a fire and sat as close to it as possible but I was still cold. I bathed with warm water but the coldness did not stop. I went to sleep. By the morning time I was still feeling cold, even when I had covered myself with two blankets and when I was sitting under the sun. I used the money I had earned to go and buy medicines from a clinic in Kirombe. After swallowing the chloroquine and Action* [paracetamol–acetyl salicylic acid–caffeine] *tablets I vomited them. Even the next day I vomited the medicines. I could not drink or eat anything, not even cold water. I was drinking only warm water. I bought two more tablets of chloroquine and Panadol* [paracetamol]. *The landlady instructed me to take the tablets with warm water. After 2 days I started feeling better though I was still very weak and dizzy. I had a slight headache and by the end of the week I had recovered completely. I have not fallen sick again for 1 month now.*

Acan, a 10-year-old girl, shared her experiences verbally:

> *'It started by feeling* koyo [coldness/shivering or fever] *and later with* ngok [vomiting], *and I had* abaa wic [headache]. *I did not come to school that Tuesday. My older sister, who is 13 years' old, told me to bathe and go and buy medicines for malaria. She gave me 100 shillings* [equivalent to €0.04 at the time of the interview] *for chloroquine and 50 shillings* [€0.02] *for Panadol. I brought two tablets of chloroquine and two*

Panadol. I took them but the next day my body started itching. My sister bathed me and took me to Gulu Hospital. By that time I could not talk and was told to get 10 injections [of quinine] *at the hospital. After 3 days I started feeling better and decided to go to the well to fetch water, but when I came back, I was feeling cold, had a stomach ache and started vomiting again. I also had diarrhoea. I was taken back to the hospital by my grandmother. That time I was given Fansidar* [sulfadoxine–pyrimethamine] *and Panadol and* yat acholi [herbal or Acholi medicines] *from home. It was* kor muyeme [mango-tree stems] *and* lace [unknown plant species] *for malaria. Then I started feeling better. I was also given orange and passion-fruit juice to drink.'*

Over 400 children wrote about or narrated their experiences with illnesses (that they sooner or later diagnosed as 'malaria') that they had suffered from in the previous month. Children described 'malaria' as *malaria madongo* (severe malaria), *koyo ki lyeto* (coldness and high body temperature) and/or *abaa wic* (headache).

When, in the interviews based on semi-structured questionnaires, 165 children were asked 'What illness experience or health problem affected you in the last month?', 16 complaints were mentioned (see Table 1).

The symptoms described by the children, in conjunction with clinical diagnosis at the local hospitals, health centres and private health providers, and supported by the choice of medicines the children eventually procured, were reclassified into 'illnesses' as summarized in Table 2. The illness experiences described by the children as *malaria madongo*, *koyo ki lyeto* and/or *abaa wic*, for example, were reclassified as 'malaria'. Since no gender differences were observed in any of the 'malaria'-associated symptoms, data for the two genders were subsequently pooled. Table 2 shows that 'malaria' was the most commonly identified 'illness', directly followed by 'diarrhoea' and 'cough and influenza'.

TABLE 1. *The illnesses and health complaints that the 165 interviewed children said they had experienced in the month prior to the interviews*

Illness or symptom		No. of interviewees			
As reported, in Acholi	Translated into English	Boys	Girls	All	$P^{\star}$
Aona ki avuru	Cough and influenza	76	68	144	
Gwinyo	Scabies	83	33	116	<0.05
Tyena lit/wang vu	Wounds and injuries	38	57	95	<0.05
Amwoda ici	Stomach ache	22	61	83	<0.05
Cado	Diarrhoea	40	35	75	
Cado pii pii	Watery diarrhoea	32	30	62	
Lyeto	Fever	35	24	59	
Malaria	Malaria	20	21	41	
Lit wang	Red eye	15	23	38	0.05
Trachoma	Trachoma	17	12	29	
Koyo	Coldness	13	12	25	
Abaa wic	Headache	11	14	25	
Twol okayan	Snakebite	17	2	19	<0.05
Cado marac/Cado remo	Bloody diarrhoea	9	4	13	
Malaria madongo	Severe malaria	5	3	8	
Two cimu	Epilepsy	1	1	2	
	Any illness or symptom	434	400	834	

*For the inter-gender difference in frequency.

TABLE 2. *The results of reclassifying the results shown in Table 1 into eight main categories of illness among the 165 interviewees*

Illness	No. and (%) of the reported episodes of illness
Malaria	158 (19)
Diarrhoea	150 (18)
Cough and influenza	144 (17)
Scabies	116 (14)
Wounds and injuries	95 (11)
Stomach ache	83 (10)
Eye infection	67 (8)
Other	21 (3)
Any	834 (100)

According to the reports of the 24 children who were extensively followed-up over 6 months, each of these children suffered a mean of three episodes of clinically diagnosed or self-diagnosed 'malaria' during the follow-up period.

Analysis of medical records during a month-long observation at the state-aided out-patient units of the GRRH in Gulu and the health centres in Laliya, Layibi and Laroo showed that 70% of the children aged 8–16 years who presented at these institutions were diagnosed as having malaria. All of these diagnoses were clinical and none was confirmed parasitologically.

TABLE 3. *The reported frequencies of drug use among the 165 interviewed children, in the month prior to the interviews*

Drug	No. of uses
Antibiotic	449
Antipyretic*	245
Mebendazole	80
Psychopharmaceutical	250
Antimalarial	226
Ointments for scabies	128
Multivitamins	104
Eyedrops (gentamycin)	98
Any	1571

*Panadol™ (i.e. paracetamol; GlaxoSmithKline, Brentford, U.K.) or Action (i.e. paracetamol–acetyl salicylic acid–caffeine; Beta Healthcare International, Nairobi).

In response to an open-ended question about the drugs that the 165 interviewed children had used in the previous month, 19 different drugs or drug combinations were mentioned (Table 3). Together, the 165 interviewees had used drugs on 1571 occasions in the previous month. The exact identity of the drugs used was not always clear and this was particularly the case for the antibiotics, with many children only able to describe the appearance of the antibiotic capsules they had used. In some cases, however, with the help of three pharmacists in Gulu, the probable active ingredients could be identified from the colour of the capsules. Identification of the drugs used for 'malaria' was more straightforward: white tablets of chloroquine were bought from many different vendors and recognised by their bitter taste; sulfadoxine–pyrimethamine was the only other antimalarial drug available from drug vendors and markets, as tablets of Fansidar® (F. Hoffmann–La Roche, Basel, Switzerland); and quinine was only received by injection and by children who, although believed to have malaria, had not responded to treatment with chloroquine or sulfadoxine–pyrimethamine. Quinine was bought from drug vendors or at hospital pharmacies. More often than not, whether they had bought or had been given the drugs, the children took an incomplete treatment course (often just a single tablet or capsule). The artemether–lumefantine (Coartem®; Novartis, Basel, Switzerland) and other artemisinin-based drugs that, at the time of the present study, were recommended for malaria treatment by the Ugandan Ministry of Health were never mentioned by any of the children.

The children had purchased the pharmaceutical drugs that they had used from 'drug shops' (29%), clinics (27%), hospitals (21%), and undetermined sources that were often far away (23%). Apart from these drugs, herbal medicines were frequently used, more frequently by the boys than by the girls. In the month prior to the interviews, the 165 interviewees reportedly used

herbal medicines (mango roots and bark, pawpaw leaves, garlic, banana sap, neem leaves, and guava leaves and bark) a total of 595 times.

Drugs to alleviate the signs of 'malaria' included antimalarials (226) and antipyretics (245), with these two types of drugs often taken together (Table 4). No reliable information on the doses used could be collected.

Of all the drugs bought or received by the interviewees in the month prior to the interviews, 30% were used to alleviate the symptoms of 'malaria'.

DISCUSSION

According to MSF, malaria is the main cause of human morbidity in northern Uganda, both in the population as a whole and among children aged <5 years, accounting for 47% and 51% of all episodes of illness in these two groups, respectively (www.msf.or.jp/news/baseline/Baseline.pdf). Although the human malaria in the Gulu area should probably be characterised as holo-endemic (Prugger *et al.*, 2008), there are few reliable data of relevance.

One of the main findings from the narratives recorded in the present study is that the children investigated considered 'malaria' as the major cause of morbidity and took refuge in extensive self-medication to treat this ailment. Elsewhere in Africa, malaria tends to be heavily over-diagnosed in clinics and dispensaries where sound diagnostic facilities are lacking or underutilized (Amexo *et al.*, 2004). A similar level of over-reporting is likely to have taken place among the displaced children who participated in the present study. The incidence of 'malaria' reported by the 24 children who were the respondents in several in-depth interviews over half a year — a mean of three episodes/6-month period — seems exceptionally high (and probably far too high to be a believable estimate of the true incidence) for a presumably semi-immune population of children aged 8–16 years living in an area with holo-endemic malaria (Reyburn *et al.*, 2005). Although the children investigated were not part of a stable, well-settled population, many of them having moved into their present place of residence from elsewhere, most would have lived in malarious areas all of their lives. Unfortunately, a self-diagnosis or clinical diagnosis of malaria is probably the 'easy option' in an area where the facilities for making a reliable alternative diagnosis are absent or very scarce. The perceived link between fever/headaches/vomiting and malaria, the potential severity of the disease, its commonness, and its treatability with relatively cheap drugs that are available in even the most basic of the local drug shops together lead to an exuberant claim for a 'pole position' for malaria, as the cause of misery and disease. The true prevalence of malaria and the degree of over-reporting, in the present study area and in many other endemic areas, need to be established using parasitological or molecular methods.

Although the consumption of one or two tablets of chloroquine or sulfadoxine–pyrimethamine is unlikely to result in the effective treatment of malaria, it may give some symptomatic relief, especially from fever. Children who take such small doses of antimalarial drugs may therefore still consider the treatment as 'helpful' or, even, 'effective'. Data to assess the merits of incomplete chloroquine or sulfadoxine–pyrimethamine treatments are lacking. Even complete courses of treatment with chloroquine or sulfadoxine–pyrimethamine may be ineffective in the study area because of

TABLE 4. *Frequencies of drug use for the management of 'malaria' within a 1-month recall period, as reported by the 165 interviewed children*

Drug	No. of uses
Chloroquine	149
Fansidar (sulfadoxine–pyrimethamine)	55
Quinine	22
Panadol (paracetamol)	156
Action (paracetamol–acetyl salicylic acid–caffeine)	89
Any	471

parasite resistance but, again, the relevant data are lacking. The fairly frequent mentioning of *malaria madongo* in the children's narratives — indicating cases of malaria who did not respond to chloroquine or sulfadoxine–pyrimethamine — is perhaps an indication that non-responsiveness to the commonest antimalarial drugs in the study area is a frequent event. If parasite resistance is already common, there is probably no great need to reduce the mis-use of chloroquine or sulfadoxine–pyrimethamine, in the treatment of children who do not really have malaria, as a way of slowing the development of such resistance (Francis *et al.*, 2006).

Children suffering from malaria require effective antimalarial treatment. Artemisinin-based combination therapies (ACT), which have been shown to be highly effective in reducing malaria-related mortality and morbidity in numerous countries (Ogbonna and Uneke, 2008), would probably be useful among the children of Uganda, especially in areas where the effectiveness of chloroquine and sulfadoxine–pyrimethamine are dwindling. ACT tend to be relatively expensive, however, making the accurate diagnosis of malaria (and the avoidance of over-treatment) even more important.

The pragmatism of the children investigated in the present study — in their quest for therapy and resolution of their physical (and mental) problems in a harsh and miserable environment — was an essential part of their survival. The placing of an erroneous label of 'malaria' on too many of their episodes of illness obscures, however, the real causes of much of their poor health. The inadequacy of the existing healthcare system, to arrive at reliable alternative diagnoses, encouraged the children towards inaccurate self-diagnosis and, consequently, to ineffective treatment.

What, then, are the measures needed to support and improve the children's strategies for improving their health? A solid set of measures to reduce the risk of getting malaria, such as the provision of impregnated bednets and indoor residual spraying, should probably be promoted but, if much of the 'malaria' among the children is not really malaria, it may not trigger a dramatic reduction in morbidity. Improvements in the functioning and affordability of the local health services, including improvements in the diagnostic services for malaria and the other major causes of illness, would perhaps be more beneficial, especially if accurate diagnosis can be combined with appropriate treatment for each disease.

The availability of antimalarial and other drugs from the private sector creates an opportunity for the children in and around Gulu to cope actively with the health problems that they are facing. Unfortunately, in the absence of easy access to professional healthcare providers, the children often have to use a trial-and-error approach involving both self-diagnosis and self-medication. An important fraction of the drugs sold by the private sector, in small pharmacies and markets, is likely to be of a poor quality and ineffective (Taylor *et al.*, 2006). Even if the drugs that the children obtain are effective, the dosages that they use are mostly too low to guide the children effectively in learning to use the right drugs (Taylor *et al.*, 2006). In addition, doses that are too low to be effective promote the development of resistance in the target pathogens. This holds true not only for the antimalarials but also for the antibiotics. If the local diagnostic system does not improve, so that malaria can be reliably diagnosed and the alternative diagnoses can be confirmed or rejected, the current over-consumption of antimalarial drugs may simply be replaced with an over-consumption of antibiotics.

Since the peace negotiations ended the civil war in northern Uganda, many of the displaced people have returned to their villages. Most of the displaced children who live in child-headed households and most of the other children who have to fend for themselves have, however, been forced to stay in the IDP camps, as the care structures that would normally be provided by the children's extended families and home communities have been destroyed. A

very first step to improve the prospects for better health among the displaced children aged 8–16 years is the recognition of the special position of such children, who are in charge of their own health and, often, that of their younger brothers and sisters. Remarkably, one in every four households encountered in the present study was headed by a child aged 10–15 years (data not shown) who was responsible for two to eight family members. The present observations have policy implications for the provision of, and access to, healthcare services for children who have to fend for themselves, not only in Uganda but also in many other low-income countries. Sadly, armed conflicts and the HIV/AIDS pandemic are increasing the numbers of child-headed households in many areas of the world.

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